

Massage for Young People with Cystic Fibrosis: Dissemination Choices Bring Wider Access

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I had an interesting conversation not too long ago with a mid-program massage student regarding a project for her training. She and her classmates were charged with developing and scripting a treatment protocol for a particular condition of their choice. But, the exercise was to conclude with a treatment application on a classmate who will not have the condition (or symptoms) the treatment protocol has been developed for. We had a lively exchange about the challenge this exercise poses because the instructor wants a very specified, step-by-step stroke progression and application outline—but the instructions do not allow for the real-world treatment progression that tends to occur when working with an actual client with varying needs and treatment goals.

Some big takeaways of our conversation dealt with the differences in outlining a general assessment and progression process based on articulated rationale, and then specifically describing various techniques that could/would be used versus a strict listing (for example, “x” many strokes on “x” muscles in “x” order for an “x” amount of time). I have used both protocol approaches as a researcher and clinician, but each role uses treatment protocols in different ways—for distinct purposes.

Cystic Fibrosis: A Pilot Study

This Somatic Research column focuses on a cystic fibrosis (CF) pilot study that was published in the March 2019 issue of the open-access journal *International Journal of Therapeutic Massage and Bodywork* (IJTMB). The article, titled “Improving Clinical Outcomes and Quality of Life with Massage

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Therapy in Youth and Young Adults with Cystic Fibrosis: A Pilot Study,” examines clinical improvements from massage for young people with CF.¹

A big contribution this pilot study makes to the massage field is the dissemination of a detailed massage treatment protocol for people with CF, creating an evidence base that therapists—at all levels—can quickly access and implement. The protocol is very specific in its detailed description, yet its focus is more on the systematic process “scaffold” to address pain and discomfort patterns experienced by those with CF and allows for the massage therapists to incorporate clinical judgment.

About Cystic Fibrosis

CF is a genetic condition that causes abnormal salt and water movement in the body, resulting in thick, sticky mucus accumulation in the lungs and other organs.² There is no cure for CF, and treatment focuses primarily on helping to thin and clear mucus from the lungs through coughing and preventing respiratory infections.

Symptom severity can range for people with CF, but repeated daily treatment is often needed to expectorate mucus from the lungs. Life expectancy is reduced for those with CF and people tend to experience pain and muscle fatigue related to the expectorating process. Cystic fibrosis’s symptomology and continual treatment can have pronounced impact on patient and caregiver quality of life.

About the Study

The IJTMB article sought to pilot a specified and detailed massage protocol applied to young people with CF for feasibility and to describe the protocol’s effects on pain symptoms and quality of life (QoL).

Authors of the study include two massage therapists, several nurses, and a physician. The study also includes massage therapist observations, within their treatment facility over the years, while working with youth and young adults with CF. The massage therapists found the same muscle dysfunction and

postural change patterns across patients reflective of respiratory muscle overuse, fatigue, and trigger point development.

The protocol used for the study was developed to systematically address these observed patterns.

Twenty-four outpatients from the study-affiliated pediatric hospital completed the research trial.

Participants were 8–21 years old, had CF, and were randomized into a treatment or control group for the 10-week study duration.

Outcomes data (measuring quality of life, pain, and pulmonary function) were collected at baseline and at 10 weeks (study completion). Participants randomized to the massage group received 3–5, 60–to-90-minute treatments during the study on a tapered schedule, reflective of their outpatient massage therapy model. The initial treatment (Week 0: First treatment) was followed one week later with the second treatment (Week 1: Second treatment). Two weeks later, another treatment (Week 3: Third treatment) was given. During Week 6, the fourth treatment was given. The final (fifth) treatment was given four weeks after the fourth treatment, in Week 10. Those in the control group only attended data collection study visits and received phone calls at Weeks 1, 3, and 6. Control group participants received a complimentary massage at the end of the study.

Study Results

The study's small sample size limited robust statistical analysis, but some interesting and meaningful results point to the treatment protocol's feasibility and effectiveness for use in future research. As is common for this population, participants from both groups were hospitalized during the 10-week study, but fewer participants were hospitalized and fewer overall hospital admissions occurred from the treatment group.

Psychosocial, physical, and total health QoL scores for treatment group participants clinically improved compared to those in the control group. Parent physical health QoL scores also improved for the

treatment group compared to the control group. Patients in the treatment group reported less pain, greater QoL (related to ease of breathing), and improved relaxation from baseline to study completion. Also, muscle tightness was significantly less at study end for those in the treatment group compared to the control group. Those in the massage group also had improvements in their pulmonary function with increased thoracic excursion and breathing ease.

It is important to emphasize that few of the study's reported findings reached statistical significance. However, for a small pilot study such as this one, descriptive statistics highlight positive trends seen in the data and effect sizes, which can inform clinical hypothesis building and treatment planning—as well as future research designs.

The study's detailed treatment protocol is included in the article's Appendix. It outlines and describes each step of the treatment's approach process—beginning with the recipient lying on their back, progressing through several side-lying techniques, and concluding with the patient in a sitting position. Positioning and treatment application are described in detail for trigger point and myofascial work, as well as stretching and post isometric muscle release from the legs, through the sacrum, trunk, shoulders, arms, neck, and abdomen.

The study's small sample size limited the extent to which statistical significance could be obtained. But highlighted study results point to positive outcomes; feasibility confirmation regarding study design and treatment application for future research; and interesting and positive findings, including those related to condition severity, QoL, pain, and function. Massage clinicians will be able to use the research intervention protocol as a framework for treating those with CF in their practice, and educators can use the protocol as a discussion centerpiece for critical thinking or treatment-planning exercises.

Final Thoughts

It is no surprise that young people with CF benefit from therapeutic massage in regard to symptom management and QoL. While more and larger studies are needed for therapeutic massage in special populations, including CF, the evidence base is growing to support the integration of massage into usual care for this and other special populations.

Clinicians and researchers have differing views and usage motivations for treatment protocols (researchers focus on treatment replication and fidelity), but what makes this study treatment protocol really great (and implementation-ready), is its development. The study is based on years of clinical massage experience, where clinicians were able to help young people manage CF and related patterns, and observation over an extended period of time. This is exciting because few clinicians have had the opportunity to build such informed experience within a narrow population. And, the dissemination of this protocol allows early and seasoned massage clinicians to benefit from the CF expertise of these authors and massage clinicians.

Massage therapy can—and does—play an important role in symptom management for countless people from various special health populations, such as those with CF. However, with relatively little research for massage, there is a sparse literature foundation for which evidence-based massage practice can form—leaving primarily anecdotal evidence, textbooks, clinical experience, and theoretical critical thinking to inform treatment plan development.

I am so glad the authors chose to disseminate their findings and treatment protocol in IJTMB, where clinicians and CF stakeholders will have no barriers to access it. I know if I were a massage novice and had a child with CF, I would have this protocol in hand when seeking a massage therapist to work with my child for their CF-related sequelae.

My Experience

I have used treatment protocols in various ways as a researcher and former massage clinician. As a new massage therapist, I took “comfort” in a generalized one-hour full-body massage protocol that started with a prone recipient on which the massage progressed from the back, shoulders, and arms, to each leg and glute, feet and anterior legs, abs (if there was time and/or a request), arms and hands, shoulders and neck again, and ending with face and scalp work. This approach quickly evolved as my confidence, experience, and clinical knowledge increased, and I was able to drop any reliance on a set process or protocol.

After two years in practice, however, a new clinical experience left me seeking some kind of protocolized approach to provide me with a framework I could base my initial treatment plan on. The experience and environment I was entering was incredibly emotional and required a lot of “presence energy” to keep myself grounded and open to the varying needs of everyone involved. By developing and entering my first treatment with a set approach—a protocol, if you will—I was less nervous and more confident as a new clinician in this novel and complex situation.

IJTMB: Open-Access and Peer-Reviewed

The venue in which the study’s authors chose to disseminate their work is a particularly important consideration regarding the impact of this research for the field. The International Journal of Therapeutic Massage and Bodywork (IJTMB) is the sole peer-reviewed journal exclusively focused on the field of massage therapy and is the official journal of the Massage Therapy Foundation and Registered Massage Therapists Association of British Columbia. IJTMB is almost 11 years old, indexed in several systems (including PubMed Central), has a strong and growing registered readership, and, most importantly, is open access without submission or publications fees.¹

Many research journals have a fee structure, which limits accessibility in some way. Either access is based on subscription fees for the reader/end user (payment is required for article access) or authors have to pay a publication fee to the journal upon acceptance.

There are several additional points to be made here about the open-access philosophy and the rise of predatory journals that do not have the same scientific or peer-review standards as traditional research journals, but that is a topic for another day. IJTMB's open-access policy is made possible by philanthropic support from its supporting agencies. The journal maintains scientific rigor and integrity, and is critical for ensuring massage therapy clinicians, educators, and research enthusiasts are able to read and engage with research directly related to them.

Note

1. Ann Blair Kennedy, "Celebrating the 10th Anniversary of the International Journal of Therapeutic Massage and Bodywork," IJTMB 11, no. 3 (August 2018): 1–3.

Notes

1. Kathleen Zink et al., “Improving Clinical Outcomes and Quality of Life with Massage Therapy in Youth and Young Adults with Cystic Fibrosis: A Pilot Study,” *International Journal of Therapeutic Massage & Bodywork* 12, no. 1 (March 2019): 4–15.
2. Brian P. O’Sullivan and Steven D. Freedman, “Cystic Fibrosis,” *Lancet* 373, no. 9678 (May 2009): 1891–1904, [https://doi.org/10.1016/S0140-6736\(09\)60327-5](https://doi.org/10.1016/S0140-6736(09)60327-5).

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